

**Children's Special Health Services  
Family Advisory Council meeting minutes  
May 15, 2004**

Present from Family Advisory Council: Donene Feist, Cheryl Klee, Teri Walters, Lisa Beckman, Evelyn Klimpel, Carla Peltier, Lori Hanson, Twyla Bohl

Present from CSHS: Terry Bohn, Tammy Gallup-Millner, Kora Dockter, Sue Burns, Leann Bayman

Department of Health Representative: Lorie Martell. Kim Senn will be taking the place of Sandy Anseth on the Council. She was not able to attend so Lorie came in her place. Lorie mentioned that she works in the areas of school nursing, the early childhood systems grant, and with local public health departments and Head Start nurses.

**Updates**

Membership: Lisa, Lori, Donene, and Cheryl agreed to serve another two-year term.

There were no suggested changes to the Council Bylaws

There were no suggested changes to the Review/Recommendation Form or the May meeting minutes.

**CSHS Program Updates**

- Medical Advisory Council. Tammy summarized discussion from the Medical Advisory Council meeting. A draft grid was presented to the members to be used as a guide in considering new conditions to be added to the eligibility list. A motion was made and passed to use this tool. Staff reported that 97% of the children served by CSHS have a source of health care coverage. Family Advisory Council members will receive a copy of the Medical Advisory Council meeting minutes when finished.
- Multidisciplinary Clinics. Kora provided an update on the regional asthma clinic and the status of the scoliosis clinics. Kora also reported on discussion about possible legislation to allow the use of asthma medications by children in school
- Care Coordination. Kora provided an update on the two public health care coordination sites. She reported that the care coordinator in Grand Forks is getting many new referrals, often from more than one source.
- Metabolic Program. It was reported that there are 4 clinics each year and CSHS served 21 individuals last year. CSHS nursing, support and administrative staff provide state level care coordination. CSHS staff will participate on an expanded newborn screening advisory committee.
- Public Information. One member indicated she had seen a large poster with information about the South Dakota CSHCN program in a health care facility near the border and recommended CSHS consider options like this to promote the program in addition to brochures.

- Administration:
  1. Interim legislative committees are meeting on Medicaid, CHIP, and pharmacy issues
  2. Governor Hoeven has formed a committee to study the uninsured in ND. Preliminary results will be forthcoming.
  3. Flat funding is planned for the CSHS budget for 2005-2007. CSHS may consider increasing contract funding by 2%
  4. There is a new CATCH grant focusing on medical home. A committee has been formed, assessment and community meetings are planned to assess interest in implementation.
  5. The Strategic Plan within the Medical Services Division in DHS will focus on: a) success stories, b) teamwork & communication, c) innovations that improve services to clients, d) accountability, and e) legislative messages with real priorities and champions.

## **Title V Needs Assessment**

- It was reported that the CSHS Family Survey had been mailed in early April. Most of the surveys have been returned and analysis has begun. Preliminary results will be shared at the August meeting. One member reported that when she had attended one of the CSHS sponsored clinics, family members there who had received a survey questioned where it came from. She said clinic staff, although the clinic was funded by CSHS, didn't know where the survey came from either and advised families to throw it away. CSHS needs to explore ways to solve this problem.
- It was also reported that CSHS has contracted with an agency in Bismarck to conduct family focus groups and provider surveys. There will be six focus groups around the state scheduled for early June.
- Teri mentioned Dr. Cook had also done some focus groups and she will share the results of them with CSHS to be included in the 5-year needs assessment
- It was announced that a planning retreat is scheduled for October 28 and Family Advisory Council members were encouraged to attend.

## **MCH Block Grant**

- Staff and Council members went through the nine federal and state performance measures specific to CSHCN and their families in the MCH Block Grant. Members were asked to comment on proposed activities planned by CSHS for each measure for the next year beginning in October, 2004. Suggestions from members will be included in the written plan that will be included in the Grant application.
- Members completed a form ranking family participation in the state CSHS program. Some members questioned if Family Advisory Council membership should be considered as a paid consultant to the program. It was suggested that

each person use their own personal judgment. Member rankings will be averaged and combined with CSHS staff rankings for the final ranking to be submitted in the Grant application.

### **Family Advocacy Tips**

CSHS will be doing a presentation at the ND Family Connections Conference in June. The focus will be CSHCNs in ND, who they are, how can families get help, and new health initiatives with opportunities for family involvement. Information regarding family self-advocacy and systems advocacy were shared with members. In addition to this information, members suggested the following resources be shared at the conference:

- Family Voices handout
- Angry? Confused? Overwhelmed? booklet
- Paying the Bills
- PACER book (Donene will provide copies)
- Record keeping care notebook from Washington state

It was also suggested by members that it would be helpful to have a compilation of upcoming trainings, conferences, and workshops.

**Next Meeting: Saturday August 21, 2004**